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ORIGINAL PAPER

Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents

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Abstract The aim of this study was to assess the expectations of adolescents with chronic disorders with regard to transition from pediatric to adult health care and to compare them with the expectations of their parents. A cross-sectional study was carried out including 283 adolescents with chronic disorders, aged 14–25 years (median age, 16.0 years), and not yet transferred to adult health care, and their 318 parents from two university children's hospitals. The majority of adolescents and parents (64%/70%) perceived the ages of 18–19 years and older as the best time to transfer to adult health care. Chronological age and feeling too old to see a pediatrician were reported as the most important decision factors for the transfer while the severity of the disease was not considered important. The most relevant barriers were feeling at ease with the pediatrician (45%/38%), anxiety (20%/24%), and lack of information about the adult specialist and health care (18%/27%). Of the 51% of adolescents with whom the pediatric specialist had spoken about the transfer, 53% of adolescents and 69% of parents preferred a joint transfer meeting with the pediatric and adult specialist, and 24% of these adolescents declared that their health professional had offered this option. In summary, the age preference for adolescents with chronic disorders and their parents to transfer to adult health care was higher than the upper age limits for admission to pediatric health care in many European countries. Anxiety and a lack of information of both adolescents and their parents were among the most important barriers for a smooth and timely transfer according to adolescents and parents.

Keywords Adolescence · Chronic disease · Health transition · Health care survey

Abbreviations
AHC Adult health care

Mortality rates of children and adolescents suffering from chronic disorders have decreased over the past few decades, with 90% of adolescents suffering from chronic disorders previously resulting in a lethal outcome reaching adulthood nowadays [1, 14]. For an increasing number of young people with pediatric chronic disorders, a transfer to adult health care (AHC) is required for ongoing proficient health care management during adulthood. As a consequence, the concept of transition emerged, defined as a process of "a purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-orientated health care systems" [3]. Unfortunately, the transfer to AHC is still often the result of an ad hoc decision, and some adolescents even drop out of the health care system temporarily until they seek help for acute medical problems in the AHC system [17, 18, 23, 30, 32]. Such poor transition processes may have significant negative effects on morbidity and mortality in young adults [2, 10, 17].

Many publications, including recommendations on health care transition [1, 3, 21, 22, 30, 31], are based mainly on expert opinion. A number of studies have focused on the views of chronically ill adolescents and

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their parents, but a disease-specific approach was mostly applied [4, 5, 15, 16, 24, 26]. It was concluded that this disease-specific focus does not allow generalization of the results for transition recommendations [8]. For example, the anxiety of patients with cystic fibrosis about potential exposure to infection may not be of particular concern to patients with other chronic disorders [4]. In order to assess generic (i.e., non-disease specific) expectations of chronically ill adolescents and to compare them with the official recommendations such as the consensus statements of the involved societies [1, 22], studies with a larger sample size and a non-disease-specific approach are required. However, only few studies applied a generic approach and the sample sizes of these studies were small [7, 20, 27]. Also, upper age limits for pediatric hospitals vary a lot from country to country and even within Europe, but to our knowledge, no quantitative data and only a limited qualitative data [25] are available on the adolescent patients' age preference for a transfer to AHC.

The aims of this study were (1) to explore the expectations of chronically ill adolescents at two university-based pediatric hospitals prior to the transfer to AHC with regard to the best time and setting of the transfer to AHC; (2) to define the most important decisional factors of the timing of transfer as well as the most important obstacles for a smooth transition as perceived by the adolescents; and (3) to compare adolescents' perceptions with those of their parents.

Methods

A cross-sectional study was carried out with chronically ill patients aged 14–25 years who had not yet been transferred to AHC at the time of the survey. The recruitment was performed at two university children's hospitals in Switzerland with patients being treated on a regular basis (i.e., visit at least once a year) at the departments of cardiology, endocrinology (diabetes only), nephrology, neurology, pneumology (patients with cystic fibrosis only), gastroenterology, and rheumatology. These subspecialties were chosen because of their large numbers of patients with a need for long-term disease management and in order to include patients with a broad spectrum of symptoms. In pneumology, only CF patients were recruited due to the difficulty in asthmatic patients to decide whether long-term treatment by adult specialists will be needed. Patients with cognitive impairment were not included in this study.

A questionnaire was developed based on pre-existing literature [1, 20–23, 31] and pilot-tested for comprehension among adolescents with chronic disorders, and given to health professionals for expert opinion. The final questionnaire contained 28 items about socio-economic status, chronic condition (diagnosis, age at time of diagnosis and duration of chronic illness), health status (self-perceived health status, frequency of having missed school/work, and of admission to hospital due to the chronic illness), self-perceived patient relationship with pediatric specialist, and other health professionals, stage and subjective view of their own transition process (having discussed transition with pediatric specialist, age and setting preferences to transfer to AHC), and items about their view on transition issues in general (age preference, most important factors for decision of time of transfer and perceived obstacles for smooth transfer). In addition, data were collected from the patients' parents. The 27-item questionnaire for parents included similar items regarding transition issues where appropriate.

The anonymous questionnaires were mailed separately to parent and child with a pre-stamped envelope and returned to the investigators by postal mail. It was emphasized in the instructions that adolescents and parents should complete the questionnaire separately. Two waves of reminder letters were mailed to the potential participants. For the third wave, phone calls were made if the phone number was available. Ethics consent was obtained from the regional ethics committees, and consent was received from patients and their parents prior to participation.

A total of 480 adolescents and their parents were invited to participate in this study and 298 adolescents (62%) and 331 parents (69%) completed the questionnaire. The reasons for not wanting to participate in this study were mainly that adolescents did not perceive to suffer from a chronic condition or that the chronic disease was perceived to be cured although some patients/parents did not indicate a reason for not wanting to participate. Of the adolescent questionnaires, 14 had to be excluded for reasons such as the adolescents being younger than 14 years or language difficulties. Of the parent questionnaires, 13 had to be excluded for the same reasons. The final analysis included the completed questionnaires of 283 adolescents and 318 parents (53% mothers).

The results were analyzed using SPSS 11.0 (SPSS Inc., Chicago). Where appropriate, the adolescents' expectations were tested for the adolescents' age, duration of illness, gender and self-perceived health status; and the expectations of adolescents and parents were compared with each other. The statistical analysis included frequency analysis including confidence intervals, *t* test for continuous data, chi square test for categorical data, as well as Spearman's rank correlations and Mann–Whitney *U* test for non-parametric data.

Results

The sample characteristics of the adolescent participants are summarized in Table 1.

Table 1 Sample characteristics of adolescent participants

	n=283	
	Years	%
Median age	16.0	
Age range	14–25	
Gender (% female)		56
Time since diagnosis of chronic disorder (median (range))	8.0 (1–23)	
Participants with congenital chronic disorder		20
Self-perceived health status		
Excellent or very good		49
Good		42
Fair or poor		9
Having missed school/work during last 12 months		
Never or almost never		77
At least once a month		18
Once a week or almost daily		4
Having seen their family physician during last 12 months		
Never		46
Once or twice		28
Three times and more		26
Having seen their pediatric specialist during last 12 months		
Never		3
Once or twice		35
Three times and more		62
Hospitalization during last 12 months		
Never		74
Once or twice		16
Three times and more		9

Table 2 Best age to transfer

Age	Adolescents (*n*=283)		Parents (*n*=318)	
	%	95% CI	%	95% CI
13 years or less	0.4	−0.3/1.0	0.3	−0.3/0.9
14–15 years	3.2	1.1/5.2	3.1	1.2/5.1
16–17 years	29.7	24.4/35.0	23.3	18.6/27.9
18–19 years	49.8	44.0/55.7	50.6	45.1/56.1
20 years or older	13.8	9.8/17.8	19.5	15.2/23.9
Missing answers	3.2		3.1	

Best age to transfer from pediatric to AHC in general (Table 2) For adolescents, the peak preference was 18–19 years (50%), followed by 16–17 years (30%), and 14% said that the best age for transfer would be 20 years and older. There was a significant positive correlation between the adolescents' preference of the best age to transfer and the adolescents' age (Spearman's rho=0.39; $p<0.001$) and with the duration of their illness (Spearman's rho=0.20; $p=0.001$), but neither with gender (Spearman's rho=−0.06; $p=0.32$) nor with self-perceived health status (Spearman's rho=0.07; $p=0.25$). With regard to potential differences between subspecialties, the subsamples were not large enough to perform a comprehensive statistical analysis but the peak age preference to transfer was similar to the total sample.

There was a weak but statistically significant correlation between the adolescents' and their parents' view of the best age to transfer (Spearman's rho=0.08; $p=0.04$) as 51% of the parents reported that 18–19 years would be the best ages (Table 2).

Personal age preference to their own transfer to AHC Forty-seven percent of adolescents indicated that the pediatric specialist had never talked about a potential transfer so far. These adolescents were younger (median age, 15.0 years) than those with whom the specialist had talked about their transfer (median age, 17.0 years; $p<0.001$). For those adolescents to whom the pediatric specialist had suggested an individual schedule for the transfer within the next 3 years (43%), there was a high positive correlation with the adolescent's personal preference to transfer (Spearman's rho=0.76, $p<0.001$). However, only 46% of the adolescents had indicated a personal preference, while 36% of the adolescents said that they did not care about the timing of transfer and 17% of the adolescents declared that they did not wish to change specialists. There was no age or gender difference between those who cared about the best timing for their transfer and those who did not care. However, the self-perceived overall health status of those who did not care about the best timing for their transfer was significantly better ($p=0.03$). When comparing those adolescents who did not want to change their specialist with those who did not mind to transfer to AHC, there were no differences of age, gender or duration of illness found.

Most important factors for the decision of the timing of transfer (Table 3) Chronological age was perceived by 39% of adolescents as the most important factor for the decision of the timing of transfer, followed by the adolescent feeling too old to see the pediatric specialist (34%). There was neither a significant gender or age

Table 3 Most important factor for decision of timing of transfer

	Adolescents (n=283)		Parents (n=318)	
	%	95% CI	%	95% CI
Chronological age	38.9	33.2/44.6	34.1	28.8/39.2
Adolescent feeling too old to see a pediatric specialist	34.3	28.8/39.8	36.6	31.2/41.8
Severity of chronic disease	3.5	1.4/5.7	4.4	2.2/6.7
Relationship with pediatric specialist	11.3	7.6/15.0	16.4	12.3/20.4
Parents' opinion	1.4	0.0/2.8	2.2	0.6/3.8
Other; Educational transitions (e.g., starting apprenticeship, university)	7.4	4.4/10.5	4.1	1.9/6.3
Missing answers	3.2		2.2	

difference, nor a difference in self-perceived health status with regard to chronological age or feeling too old being perceived as the most important decision factors. Severity of the chronic disease was perceived as one of the least important factors for the timing of transfer for the adolescents (4%). Similar rankings were found for parents.

Most important barriers for transfer (Table 4) Feeling at ease with the pediatric specialist was seen as the most important barrier for a successful transfer to an adult specialist by 45% of adolescents, followed by anxiety of not knowing the adult specialist (20%), and a lack of information about the adult specialist and AHC in general (18%). Among parents, feeling at ease with the pediatric specialist and lack of information were the most frequently reported obstacles for a smooth transition.

There was a significant age difference for the adolescents, as those who perceived a lack of information as the most important barrier (17.0±2.4 years) were older than those who did not (16.1±1.7 years; p=0.008); but there was no significant age difference for anxiety as the most important barrier. Gender and self-perceived health status had no significant influence on the perception of the most important barrier for a smooth transfer.

Setting and location of first meeting with adult specialist (Table 5) A total of 48% of adolescents perceived a joint transfer meeting at either the pediatric clinic or the adult specialist's clinic as the most preferable setting, with no age difference for this preference (p=0.79). The preference of parents for joint transfer meetings for their child was even higher (67%). Thirty-seven percent of the adolescents did not care about the setting, with no statistically significant age difference. However, more male (44%) than female adolescents (32%) did not care about the setting (p=0.04), and there was a trend concerning the adolescents with a poorer health status caring more about the setting (Spearman's rho=0.12; p=0.05).

Of the 51% of adolescents with whom the pediatric specialist had already talked about a transfer to AHC, a total of 53% of adolescents perceived a joint transfer meeting with both the pediatric and the adult specialist as the most preferable setting, with no age difference for this preference. Of these adolescents, 24% reported that the pediatric specialist had mentioned the option of a joint transfer consultation at either the pediatric (14%) or the adult specialist's clinic (11%).

Table 4 Most important barriers for smooth transition

	Adolescents (n=283)		Parents (n=318)	
	%	95% CI	%	95% CI
Feeling at ease with pediatric specialist	44.5	38.7/50.3	37.5	32.1/42.7
Anxiety because of not knowing the adult specialist	20.1	15.5/24.8	24	19.2/28.6
Lack of information about adult specialist/adult health care services	18.4	13.9/22.9	26.5	21.6/31.3
Parents' preference	3.9	1.6/6.1	3.8	1.7/5.9
Other	6	3.2/8.8	3.8	1.7/5.9
Missing answers	6.7		4.1	

Table 5 Preferred setting and location for meeting the adult specialist for the first time

	Adolescents (n=283)		Parents (n=318)	
	%	95% CI	%	95% CI
Meet both pediatric and adult specialist at pediatric hospital	24.7	19.7/29.8	34.6	29.7/40.2
Meet both pediatric and adult specialist at adult hospital	23.3	18.4/28.3	32.7	27.8/38.2
Meet adult specialist alone at adult hospital	13.1	9.1/17.0	17.3	12.9/21.1
Adolescent does not care/parent does not care for their child	37.1	31.5/42.7	12.3	8.4/15.6
Missing answers	1.8		3.1	

Discussion

To our knowledge, this is the first study that focused on non-disease-specific preferences of chronically ill adolescents and their parents focusing specifically on the best timing to transfer to AHC and the setting this should take place in. There was a high agreement between adolescents and their parents with regard to age preference, most important factors for decision of timing, most important obstacles, and the setting for the transfer. A majority of chronically ill adolescents preferred the ages of 18–19 years and older to transfer to AHC, although there might be some variation in this age preference depending on the availability and setting of specific adolescent specialty clinics in some pediatric institutions. This age preference coincides with other transitional tasks such as finishing secondary education or an apprenticeship and starting university studies or regular work. As some of these transitional tasks (e.g., final school exams) can be stressful for some adolescents, independently of their chronic disease, it has been recommended that the transfer to adult services should be timed to occur/take place after major educational and physical milestones [31]. Reiss et al. made the assumption that if the health care transition is initiated early enough as an active process of increasing the patient's autonomy, this may also facilitate transition in other areas of life [19]. Overall, the adolescents' preference to transfer to AHC does not discharge health professionals from assessing each adolescent's readiness on an individual basis in order to avoid a transfer at times of medical or psychosocial crisis [21, 28] which was also one of the principles of a successful transition defined by the Society for Adolescent Medicine [22]. With regard to a transfer to AHC at the age of 18–19 years and older, it is important to note that in many European countries the official upper age limit is 16 years or even lower for admission to pediatric hospitals [6], although unofficially, some pediatric hospitals allow admission of older patients under certain circumstances. This is in contrast to countries such as the USA where the upper age limit is 21 years [12]. There is a similar problem in Switzerland where this study was carried out due to inconsistent upper age regulations for admission to hospital of patients with chronic disorders 16 years of age and older, and even more variations of upper age limits for outpatient care. Therefore, it may be advisable to adapt upper age limits of pediatric health care systems, if necessary, in order to ensure a developmentally appropriate transition process for chronically ill adolescents. However, a smooth transfer to AHC will not be achieved by simply increasing upper age limits for pediatric hospitals unless appropriate standards of transition care are applied.

As might be expected, there was a significant correlation between both the adolescents' age and duration of illness and their preference for best timing of transfer, as older adolescents and those having been diagnosed for a longer time with a chronic disorder preferred higher ages for transfer. This may be explained in part by a long-lasting relationship with their pediatric specialist, given that feeling at ease with him or her was reported as the most important obstacle for the transfer to AHC. Recent literature focused more on the evidence that pediatric health professionals may be overprotective and reluctant to transfer chronically ill adolescent patients after having cared for them for many years [21, 28]. However, our data provide some evidence that for chronically ill adolescents, feeling comfortable with their long-known pediatric specialist may be a major barrier for a successful transition to AHC and that reluctance to "let go" may be an obstacle for both patients and health professionals.

The perceived lack of information about the adult specialist and AHC in general seems to be a major obstacle for transition for adolescents, and in particular for older adolescents, and even more importantly for parents. This is of importance as, despite the health professionals' support for increasing autonomy and self-responsibility of chronically ill adolescents, the existing literature supports the need to include the patient's family in the planning of the transition process [1, 21]. The perceived lack of information about AHC may be due to the failure of transition planning. Transition protocols that include guidance about appropriate levels of information to be provided to adolescents and parents at regular intervals could be helpful in starting early enough with provision of information and by supporting autonomy and self-responsibility as the basis to develop/build a well-planned time schedule for a smooth transfer [9, 21, 22]. However, a recent study from Australia showed that a documented transition plan was available only among 13% of young adults older than 18 years and treated at a pediatric hospital [11] providing evidence of failure of transition planning. Another recent study from the USA which focuses on adolescents aged 12–17 years with special health care needs also showed evidence for the lack of transition planning with only 41% of adolescents having had discussed the issue of transfer to AHC [13]. In our study, 51% of young people aged 14–25 years indicated that the pediatric specialist had talked about the transfer to AHC.

Half of all the adolescents and two thirds of their parents showed a preference for joint transfer meetings with both the pediatric and the adult specialist when meeting the adult specialist for the first time. However, of those adolescents with whom the pediatric specialist had talked about a transfer to AHC, only one in four was offered a joint transfer meeting. Joint transfer meetings may have the potential to provide in-depth information about AHC and to decrease the anxiety for adolescents and their parents about treatment of the chronic disease with an unknown adult

specialist within the AHC system [4]. In addition, joint transfer meetings and other settings of transition programs such as an earlier integration of the adult specialist team into care (e.g., transition clinics) could potentially reduce levels of anxiety and improve continuity of care [4, 17, 21]. If geographical distance is an obstacle for joint meetings, other frameworks of support such as a health navigator system may be helpful in providing appropriate information to the adolescent patient during the transition process [29]. Some institutions also provide adolescent specialist clinics for young people (in collaboration with pediatric and adult specialists) in order to allow a more gradual transfer to AHC.

The non-disease-specific approach of this study allowed to recruit a relatively large sample size of chronically ill adolescents from seven different pediatric specialties. A limitation of this study was that the sub-samples sizes of the specialties did not allow for comparisons between different groups of chronic disorders. However, the aim of this study was to focus on chronically ill adolescent patients in general in order to draw conclusions for all of these patients rather than focusing on disease-specific subgroups of adolescents. Another potential limitation was that with the questionnaire completion at home, independent completion of the adolescent and parent questionnaires was not guaranteed, although the adolescent and parents were advised to do so. Furthermore, it could be argued that the results of this study may be influenced by the Swiss health care system, e.g., tradition of age limits for access to pediatric hospitals and AHC. However, with no clear consistency of hospital regulations in Switzerland, this seems unlikely.

In summary, pediatric institutions, in collaboration with AHC, can facilitate a smooth transition of adolescents and their parents from pediatric to adult health care with the introduction of transition protocols. These protocols should provide guidance for an early start of the transition process, appropriate levels of patient information, developmentally appropriate upper age limits in pediatrics, and recommendation for suitable settings of transfer.

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Conflict of interest The authors declare that they have no conflict of interest

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